Why does Ethics Matter in Participatory Health?

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Abstract. Social media and participatory health has emerged as a promising tool for health, including developing diagnostic tools and therapeutic interventions. In the realm of online health care delivery, artificial intelligence based counseling apps now enable patients to consult with a chatbot instead of an actual therapist. However, several ethical issues and implications became relevant with this shift to digital interventions and healthcare delivery. This panel will describe ethical issues related to recent developments in participatory health and social media including the digital exposome, importance of involving patients in the design of AI-based applications and ethics of social media research in healthcare.

Keywords. Participatory health, social media, ethics, mHealth, digital exposome

1. Introduction

In recent years, the digital transformation in healthcare has led to an integration of social media, wearables, mobile applications etc. into treatment programmes. Many health interventions delivered via mobile applications demonstrate similar efficiency as standard therapies. Clinical trials are run by means of mobile apps collecting sensor data or patient reported outcomes (e.g. Ally Science, http://allyscience.ch). Social media are used for patient recruitment in clinical trials [1]. Already in previous work, ethical issues related to participatory health and social media were collected and discussed [2]. However, the interest and awareness of ethics in this field increased in the last 5 years. Furthermore, new technologies have become increasingly relevant e.g. conversational user interfaces, artificial intelligence, digital exposome and digital biomarkers raising additional ethical implications. Thus, this panel will explore ethical issues related to recent developments in participatory health and social media as well as open issues that have not been addressed previously such as transparency or trustworthiness of AI-based systems [3,4].

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2. Brief outline of the presentations

The panel comprises five short presentations followed by a discussion with the audience. As a collaboration between the IMIA Participatory Health and Social Media Working Group (IMIA PHSM WG) and the Exposome Informatics Working Group Data Mining and Big Data Analytics Working Group, this panel brings to bear the effort and resources of a diverse range of IMIA working group membership.

Luis Fernandez Luque will address the importance of involving patients in the design of AI-based digital health solutions. He will elaborate how patients will be involved in a project on AI for cancer [5]. Digital health solutions are becoming increasingly personalized by the use of AI algorithms and data-driven personalization techniques. Many potential ethical challenges are emerging from this trend of pervasive data-driven personalization including privacy concerns, concerns of providing personal data and data quality.

Guillermo Lopez Campos will address the opportunities that arise from digital biomarkers while highlighting the imperative necessity to address the ethical challenges associated with monitoring individual's digital lives. He will explore the ethical implications that may arise from discovering incidental or secondary findings associated with the use of digital biomarkers and exposures. In recent times, there has been a movement to define digital biomarkers, as any type of digital measurement that can be used as a marker for a relevant biomedical process. Simultaneously, there is an increasing interest in studying the digital environment, how it can be monitored and how it can affect individuals in an area that we describe as the digital exposome [6].

Elia Gabarron addresses ethical issues of social media for patient recruitment into research, for patient-healthcare provider communication and for health promotion. When using social media for patient recruitment into research, privacy and confidentiality issues should be a priority for the healthcare professional [2]. Healthcare providers willing to communicate on social media with patients must be aware of the risk of infringing on patient' privacy and confidentiality, breaking standard procedures [7].

Carol Bond reflects on ethics of online (qualitative) research. As well as being a place to recruit research participants, social media provides a rich source of information for researchers. Where this information collated, anonymized and used quantitatively relatively few ethical issues arise, although all researchers should ensure that appropriate ethical approval is sought. The issues when the information is analyzed qualitatively however are more challenging. Research has found that people who participate in online discussion boards do not object to the information they post being used in an aggregated form [8], but whilst there was agreement that they had put their information in the public domain the use of direct quotations was problematic for some people. Research methods need to change to reflect the rapidly developing world of social media.

Finally, *Kerstin Denecke* outlines ethical aspects related to health chatbots. Interacting with a system in a human-like manner gained momentum with symptom checkers, bots who educate patients [9], or even apps that deliver cognitive behavior therapy. While technology targets developing chatbots that are as human-like as possible, this can become critical in healthcare. Users might forget that they are talking to machines, rely entirely on them and underestimate potential health risks. The underlying knowledge base has to be evidence-based to avoid patient harm due to incorrect or life threatening bad advice.

3. Brief biographies of the panelists

Dr. Kerstin Denecke is a professor of medical informatics at Bern University of Applied Sciences, Switzerland. She is a member of the German Society of Medical Computer Science, Biometry and Epidemiology (GMDS) and IMIA PHSM WG. Her research interests include medical language processing, information extraction, sentiment analysis, and text classification.

Prof. Dr. Carol S Bond leads the Caring for Lifelong Health Research Centre at the University of Wolverhampton in the UK. She is the deputy editor of the BMJ Health & Care Informatics journal. Her research interests are around how people living with long term conditions use the internet and social media to support their own self management strategies.

Luis Fernandez-Luque graduated from his PhD at the University of Tromso (Norway) and studied computer engineering at the University of Sevilla (Spain). He has been involved in digital health research for 15 years, working both in industry and academia in institutions. He is currently the Vice President for Working Groups and SIG at the International Medical Informatics Association. He is co-founder of Adhera Health (California, USA) and Salumedia Tecnologias (Seville, Spain).

Dr. Elia Gabarron is senior researcher at the Norwegian Centre for E-health Research, University Hospital of North Norway. She is Co-Chair of the IMIA PHSM WG, and Associate Editor of the BMC Medical Informatics and Decision Making journal. Her research interests are centred around the use of social media for health, and especially its role in supporting and educating people to prevent and manage health conditions.

Dr. Guillermo Lopez Campos is lecturer in Biomedical Informatics in the Centre for Experimental Medicine, Queen's University Belfast. He is currently member of several IMIA working groups. His research interests cover different aspects related with the analysis and information management in translational bioinformatics and exposome informatics.

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